

ORIGINAL RESEARCH

Managing Multiple Chronic Conditions during COVID-19 Among Patients with Social Health Risks

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Background: Optimal care for persons with multiple chronic conditions (MCC) requires primary and specialty care continuity, access to multiple providers, social risk assessment, and self-management support. The COVID-19 pandemic abruptly changed primary care delivery to increase reliance on telehealth and virtual care. We report on the experiences of individuals with MCC and their family caregivers on managing their health and receiving health care during the initial pandemic.

Methods: Semistructured qualitative interviews with 30 patients (19 English speaking, 11 Spanish speaking) plus 9 accompanying care partners, who had 2+ primary care encounters between March 1, 2020, and November 30, 2020, 2+ chronic conditions, and 1 or more self-reported social risks. Questions focused on access to and experiences with care, roles for care partners, and self-management during the first 6 months of the pandemic.

Results: Participants experienced substantial changes in care delivery. The most commonly reported changes were a shift to more virtual relative to in-person care and shifting roles for care partners. Changes fostered new perspectives on self-management and an appreciation of personal resilience and self-reliance. Virtual care was an acceptable complement to in-person care, though not a substitute for periodic in-person visits. It was more acceptable for English speakers and with a usual provider.

Conclusion: New models of care delivery that recognize patient and family resilience and resourcefulness, emphasize provider continuity, and combine virtual and in-person care may support self-management for individuals with MCC and social needs. (J Am Board Fam Med 2024;37:172–179.)

Keywords: Caregivers, Continuity of Care, COVID-19, Family Health, Multiple Chronic Conditions, Pandemics, Primary Health Care, Qualitative Research, Telemedicine

Introduction

Optimal care for persons with multiple chronic medical conditions (MCC) requires primary and specialty care continuity, easy access to multiple providers, self-management support, identifying and

managing competing demands, goal-oriented care, and shared decision making.^{1–3} The COVID-19 pandemic abruptly changed primary care delivery to increase reliance on telehealth and virtual care and to prioritize acute and urgent care needs over chronic disease management.^{4,5}

Self-management is central to living with MCC. People must manage medical aspects of care and also adapt, maintain, and create life roles and behaviors, and cope with any emotional consequences of MCC. Family caregivers and health care providers are essential to supporting successful self-management activities and skills for this population.⁶ Effects of

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pandemic-associated care delivery changes have been investigated for populations with potentially limited virtual care access, single chronic diseases, preventive care and screening, and mental health care among others.⁷⁻¹¹ However, we are unaware of investigations into how pandemic-associated care delivery changes affected self-management for individuals with MCC.

Since the initial pandemic, virtual care options have been increasingly incorporated into routine primary care. Learnings from persons with MCC who sought primary care during the pandemic can inform clinical care redesigns that include virtual care and ensure that providers and care systems support the self-management needs of this large and growing patient population.

We sought to understand the primary care experiences of patients with MCC and self-reported social needs who obtained care during the first 9 months of the pandemic. Interviews focused on factors that may affect chronic condition self-management, and access to and experiences with health care providers. Interview participants included English- and Spanish-speaking individuals and patients who did and did not receive COVID-19-related care.

Methods

Between February and June 2021, we conducted semistructured phone interviews with English- and Spanish-speaking adults about the impact of the COVID-19 pandemic on their health care experiences and their self-management. Participants were receiving care at 2 integrated health care delivery systems (Kaiser Permanente Washington [KPWA] and Kaiser Permanente Colorado [KPCO]). This study was approved by the institutional review boards at KPWA and KPCO.

Sampling and Recruitment

We identified participants from administrative and clinical health plan data using the following inclusion criteria: being a member of either KPWA or KPCO for at least 1 year; experiencing 2 or more primary care and/or urgent care visits (phone, video, or in-person) between March 1, 2020 and November 30, 2020; having 2 or more chronic conditions from the Elixhauser comorbidity index (30 common chronic conditions associated with increased mortality risk such as congestive heart

failure and chronic pulmonary disease), answering yes to 1 or more resource needs in the prior year on the Your Current Life Situation questionnaire including financial need, housing instability, food insecurity, ADL needs, transportation barriers, and social isolation (KPWA) or reporting unmet social needs on the annual Medicare Health Risk Assessment questionnaire (KPCO) of experiencing food insecurity, needing help with 2 to 5 ADLs, or feeling lonely or isolated.^{12,13} We purposively sampled patients for variation in gender, race/ethnicity, age, and language preference (English or Spanish). Patients meeting criteria were invited to participate through a mailed letter and a follow up telephone call. All potential participants were invited to bring a care partner to the interview if desired. As with patients, care partners were verbally consented and compensated for their time.

Qualitative Data Collection

Interviewers (LT, MFG, KG, LJ, and RB) conducted 30- to 60- minute phone interviews in either English or Spanish. Demographic questions were asked at the end of the interview. Patient participants received a \$75 acknowledgment and accompanying care partners received a \$50 acknowledgment. The interviews were recorded and professionally transcribed. Spanish interviews were conducted by native Spanish speaking interviewers, professionally translated into English and then double-checked for cultural context and accuracy by these interviewers so that the transcripts could be analyzed in translation with the English language interviews.

Interview questions elicited participants' experiences accessing and receiving health care, and experiences with self-management work across 3 domains: illness work (eg, taking medications, monitoring blood pressure), everyday life work (eg, obligations to family, job), and biographical work (eg, coping with the emotions around adjusting to changes in life due to illness).¹⁴⁻¹⁶ Interview guides were piloted with volunteers and revised to optimize clarity.

Data Analysis

The coding team comprised 4 interviewers (LT, KG, LJ, MFG). Codes included a priori concepts from the self-management literature and the interview questions, such as self-efficacy and support

from family and friends, and concepts that emerged organically from the data. The coding team collaboratively coded 1 complete transcript and excerpts from 8 additional transcripts across both sites until there was agreement on the meaning and application of the codes. Care partners' responses were coded and included in analyses. There was no specific dyadic analysis with patient and care partners. Coders used Atlas.ti to assist with data management.

Once coding was complete, 2 analysts (LT, KG) examined the code density and grounded rankings to identify codes that were most frequently used and most salient to participants. These 2 analysts created coding memos for relevant codes, identified themes and organized them by the 3 topic areas in the interview guide: obtaining health care, self-management, and role of the care partner. Memos were discussed with all authors to double check interpretation and to refine themes.

Results

Thirty patient participants (18 from KPWA and 12 from KPCO) participated in phone interviews. Nine of the 30 patient participants opted to have care partners join their interview resulting in 30 patient interviewees and 9 care partners total. Patient participants were predominantly female (n = 19) and 11 chose to have their interview conducted in Spanish (Table 1).

As individuals with MCC who typically received ongoing care and self-management support, participants experienced substantial changes in the care they received during the pandemic. The most reported changes were more virtual relative to in-person care and shifting roles for care partners. These changes highlighted personal resilience and self-reliance, care partner roles, the importance of provider continuity, and balancing virtual and in-person care.

Self-Management Strategies, Self-Reliance, and Resilience

Some participants found that pandemic-related changes in care delivery, on top of pre-existing social needs such as financial constraints, fostered resilience and self-reliance, whereas others reported a sense of increased vulnerability and isolation.

Table 1. Socio-Demographics of Patient Participants

	n = 30
Age (mean and range)	60.4 (22, 89)
Gender	
Men	11
Women	19
Elixhauser morbidity score (mean and range)	4 (2, 10)
Race	
Non-white/Caucasian	15
Black/African American	<5
Asian	<5
Native Hawaiian/Pacific Islander	<5
American Indian/Alaskan Native	<5
Other	5
White/Caucasian	15
Hispanic/Spanish/Latinx	
Yes	11
Conducted interview in Spanish	11
Marital status	
Single	8
Married/partnered	11
Widowed	5
Divorced/separated	6
Employment status	
Working or in school/vocational training	5
Retired	16
Homemaker	<5
Not employed or unable to work	6
Annual income	
Less than \$10,000	5
Between \$10,000 AND \$19,999	7
Between \$20,000 AND \$49,999	14
Between \$50,000 AND \$100,000	<5
Don't know/ prefer not to answer	0

I take my medication every morning, do my blood test and make sure I record my blood sugar. I do get, from the Fresh Bucks [healthy food program] to make sure I get fruits and vegetables every month. . . After I had back pain I've been. . . stretching regularly in case my back pain returns. . . . Got to remember the stretches and I do them and they go away again. (Patient 04, English.)

Despite these challenges, many participants expressed pride in their resilience and resourcefulness in their self-management tasks with fewer visits and less available care partners. Pandemic care delivery prompted them to use different resources such as looking up health issues on the internet or mail-order pharmacy services.

I don't jump at every little thing. I know my position. I'm older, I try to watch. But you can't change age.

And I'm not going to call these people and bother them about, "I don't feel good today. I don't know what's wrong." No, I'm not like that. If there's a concern, believe me, they'll hear it. (Patient 03 accompanied by care partner, English.)

I'm social to a point, I enjoy people. But I have no problem being with myself and doing what needs to be done around my house. I enjoy reading and crocheting, and I just don't really worry. If something happens, it happens. I don't fuss and fume about it and if I don't hear from somebody, I pick up the phone and call them and say hi, I've been thinking about, how are you doing? I guess I have never really needed a lot of support. . . I don't call doctors a lot. I kind of grew up in a time that if you got sick you dealt with it. (Patient 12, English.)

My sister lives with me. She helps me when I need it, but as far as the transportation to dialysis and to go places and stuff, I have to do it. Because she works, so she's not here with me during the day. So I pretty much get up and do it. On the days of dialysis, I go to dialysis, I come back, and dialysis wipes me out. And I'll be out for the whole day mostly, until afternoon, late afternoon. . . I have to do it myself. Go to a doctor's appointment, go to the store, do whatever I need to do to take care of myself. (Patient 05, English.)

Care Partner Roles

Nevertheless, care partners remained important. Some interviewees described emotional support from family despite social distancing restrictions. This included those with self-reported mental health issues who were negatively impacted by social distancing.

I don't have a whole lot of in person friends. I have a few people that I created a moms group on Facebook and so I have connected with a lot of them. It's been interesting because I feel like I tend to help them more than they help me because they are struggling more with the pandemic than I am. But the biggest most supportive person in my life is my grandma. . . So any time that I'm having any sort of emotional problems or just feeling really like the pandemic, the day or whatever is getting to me, I just call her and she has been amazing. . . (Patient 09, English.)

In addition to providing patients with emotional and social support, family and care partners were critical to supporting the self-management work of living with chronic illness such as driving to the clinic, dropping off groceries, and coordinating with clinicians.

I have a lot of support when it comes to taking care of my health. Mainly from my daughter. She takes me to the hospital when I need it. . . to my doctor

appointments. . . She always takes me, always, always. My grandchildren . . . They're like, "Grandma, did you already take your medicine? Grandma, did you take your pills?" Every day my daughter asks me, "Mom, did you already get your pills?" always reminding me because sometimes yes. . . I feel I forget. (Patient 24 accompanied by care partner, Spanish.)

Changes in accessing care affected care partner roles. For some participants, particularly those who spoke English, telehealth visits made it less necessary for a care partner to accompany them.

Patient: They scheduled me. It wasn't no problem at all.

Care partner: It's easier—you don't have to drive there, no one has to take him, no one has to wait for him. (Patient 11 and accompanying care partner, English.)

During the acute phase of the pandemic, patients experienced challenges when care partners were not allowed to join clinic visits. This diminished patients' confidence in seeking care and detracted from care partners' ability to assist the patient at home and to be a second set of ears at the visit.

I did not like that I had to sit out in my car and wait, but that was due to the pandemic. So that was disappointing to me, because I could not be there with him. Because usually when he goes, I am there with him to see what is happening, because he might forget to tell me something, and I do not know if they are doing the right thing for him. So being not able to go into urgent care was like okay, will he even remember what they told him now, you know. (Care partner accompanying patient 10, English.)

And for the longest time, they would not let me in with her. And I understand . . . it is just difficult for me to deal with, because I've been such an integral part of everything for so long that I know the medications, I know the routines, I know the scheduling and everything. . . and there's no cell phone service in the building, either, so it was kind of like in the dark until she came out. . . (Care partner accompanying patient 01, English.)

The lack of family present during health care visits was especially challenging for non-English speakers who relied on a care partner or family member to translate.

I think so, the doctor treating me doesn't speak Spanish, she only understands a little. But my daughter always comes along and helps me interpreting

because the doctor does not speak enough Spanish. So, the doctor asks me questions and then the other way around, and so forth.” (Patient 02, Spanish.)

Experiences Accessing and Using Care

Respondents described pros and cons to virtual care. The convenience was relevant given their higher service use for multiple physical and mental conditions; however, addressing complex visit agendas associated with MCC care was described as easier in person. Provider continuity facilitated the new hybrid approach. Participants preferred in-person visits for nonverbal or nuanced communication.

For me, it’s better in person because I can tell her, “Ob, it aches here or there.” It is more flexible. (Patient 22, Spanish.)

I prefer kind of to see my doctor in person because I like to see their face when I’m talking to them, and you don’t always get that on a phone conversation. Part of it was because I kind of had a brand new doctor. I’d only been with him less than a year, so I didn’t know him well enough to get his read on things without seeing his face. (Patient 12, English.)

Although participants did not want to fully shift to virtual care, many described advantages including convenience (eg, easy scheduling, no transportation needed) and access to medical expertise for some needs. Virtual care worked well when participants had ongoing conversations with providers and had capability with the virtual technology.

He’s a great doctor. . . I like him very much. And he seems to keep a good eye on what’s going on, and he lets you know what’s going on. And I have had video chats with him. . . For me, it’s been a breeze. . . I just go in and get blood work done. I haven’t seen my care provider at all during the pandemic, but we’ve emailed back and forth, and he had to change one of my medications, and I went in and got the testing done, and it was easy. (Patient 10 accompanied by care partner, English.)

Virtual care was particularly feasible for mental health care delivery, although participants varied in their preferences. For a participant with social anxiety, virtual visits were beneficial; however, for another virtual visits risked increasing isolation.

I have a lot of social anxiety, so just being out in like open space with people in it, it just gives me anxiety. . . like when I have to see the psychiatrist, those days typically are worse than others. . . . But since I can just do it

over web cam, it’s been a lot easier. (Patient 01 accompanied by care partner, English.)

It (virtual care) just takes a while to get used to. Because I’m so used to going out, driving, go and see my doctor, my GP was a reason to get out of the house. So it . . . was like having less reason to get out of the house (sighs), it takes some getting used to. (Patient 04, English.)

Participants in this multimorbid population felt that a combination of virtual and in-person care worked best – ideally with provider continuity between encounters. Provider continuity was important for both acute and chronic care needs.

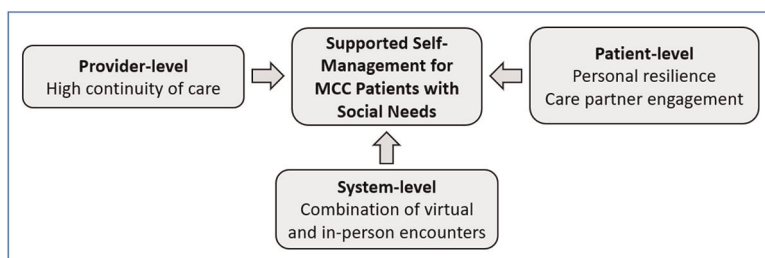
I have a pacemaker so I would go at least once a year to see a cardiologist. . . I have had a phone visit with him, but it’s not the same as actually seeing him face to face. Because maybe other questions will pop up that they don’t on the phone, because you don’t see that person. And then I have a monitor at home for my pacemaker, and they usually text for that so you don’t have to see them in person. They may do some adjustments, which they say they can do it, but I’m not sure, if you don’t visit them. Interviewer (I): What about your primary care provider? Participant (P): I did go in and I did see her. I: Would you prefer that some of those visits are in person? P: Yes, occasionally. A phone visit is fine, but not every time. (Patient 11 accompanied by care partner, English.)

I could use the Care Chat [virtual care]. They ended up calling and suggested that I make an appointment so I made an appointment for I think it was the next day, actually, because they were kind of worried about what I was talking about. So that one was actually really easy and really fast. . . . She did some tests, looked around and then she was like nope, you seem okay. (Patient 09, English.)

Discussion

These experiences with pandemic care delivery identify patient-, provider-, and system-level factors that can support self-management for persons with MCC and social needs in new models of combined virtual and in-person care. Respondents discovered reserves of personal resourcefulness and resilience that supported self-management and helped with the emotional sequelae of resource-limited chronic disease management. Care partnerships remained essential, however, and the convenience of virtual encounters for care partners supported the patient-care partner-provider partnership. For patients, virtual care was an acceptable complement to in-person care, though not a substitute for in-person

Figure 1. Factors supporting self-management for multiple chronic conditions (MCC) patients within a mixed in-person and virtual care environment.



visits. A hybrid model was perceived as more effective with provider continuity. Figure 1 illustrates these factors and provides a template for considering self-management for resource limited MCC populations.

Telehealth is effective for monitoring specific conditions and for communicating with patients who self-manage those conditions.¹⁷ Persons with MCC have found telehealth to be acceptable, improve access to care, and increase the convenience of certain services such as medication refills—although people with communication barriers or fewer resources are less able to benefit.^{18,19} Our interviews confirm these findings, and further inform how to best implement virtual MCC care: Provider continuity is important, and periodic in-person care is essential to help evaluate acute-on-chronic concerns, assess variation in ongoing signs and symptoms, and address the complex visit agendas associated with MCC. This balance is similar to recommendations for best MCC care practices elicited from health system clinicians and leaders including balancing between visit care with in-person care, addressing social risk factors, and optimizing technology for person-centered approaches to care.²⁰

Interviewees highlighted personal resourcefulness and resilience during the pandemic. Disease-specific and general self-efficacy has long been associated with improved chronic disease management and health outcomes.^{14,21,22} More recently, promoting self-efficacy has evolved to recognize patients and care partners as experts in managing their care and as equal partners with their health care team.^{23,24} Clinicians providing ongoing care for MCC patients can recognize these roles and strengths as part of new models of MCC care delivery that incorporate virtual and in-person engagement.

Learnings from Spanish-speaking interviewees confirmed previous findings that language barriers are present in both virtual and in-person settings and that non-English speakers with MCC rely heavily on family members to assist with health care communication.^{25,26} During the pandemic, limits on companions during visits was particularly distressing for Spanish speaking patients. New mixed (virtual and in-person) models of MCC care must include translation services, telephone as well as video, and other accommodations to provide patient-centered care to all MCC patients.²⁶ Similar accommodation is essential for other MCC populations such as older adults who may have limited technological literacy or communication barriers such as hearing loss.²⁵

Our study had several strengths and limitations. The study was conducted in 2 regions of a single integrated delivery system with well-established telehealth capacity and insured patients. However, our focus on individuals with both MCC and social risks expands the relevance of findings to broader populations.^{27–29} As a qualitative interview study, our findings do not generate generalizable evidence but rather suggest areas for further investigation on how to best implement new models of MCC care that rely on both virtual and in-person encounters. Further, participants' recollection of experiences during the first months of the COVID-19 pandemic may have been incomplete. We had few interviews with non-English speaking patients – the needs of diverse populations within emerging models of MCC care should be explored in more detail and perspectives of care partners should be addressed through formal dyadic analyses. Finally, we do not have the ability to separate out participants' comments relative to their experience with telephone and/or video encounters and some of their preferences may pertain more to 1 type of virtual care than the other.

Conclusion

New models of care delivery that combine virtual and in-person care can likely support self-management for individuals with MCC and social needs. However, honoring the preference for in-person visits is critical in the MCC population where good communication is essential and decision making can be highly complex. Further rigorous investigations of hybrid care models that incorporate provider continuity and recognize patients and care partners as resourceful members of the care team will inform postpandemic MCC care.

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